321 Anxiety and depression in transplant patients

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Objectives: This study evaluated emotional condition in CF transplant patients in comparison with control groups.
Methods: The Hospital Anxiety and Depression Scale (HADS), the Centre for Epidemiological Studies Depression Scale (CES-D) and State Trait Anxiety Inventory form Y (STAI) questionnaire, was administered to 12 transplant patients (group 1) and to no transplant CF patients (group 2) and healthy samples (group 3) homogeneous for age and gender (aged 20–50 years).
Data were analyzed by comparison between proportion tested with Fisher exact test.
Conclusions: The results showed an absence of anxiety and depression in group 1 vs control groups. HADS anxiety scores ($p = 0.3866$), HADS depression scores ($p = 0.2304$) and CES-D scale score ($p = 0.117$) are lower in group 1 among the controls. STAI Y-1 (state anxiety) scores confirm a lower level of anxiety among group 1 when compared with group 3. The association reaches significance at 10% ($p = 0.096$). STAI Y-2 (trait anxiety) scores, similarly, shows a greater vulnerability of the group 3 compared to group 1 ($p = 0.333$). STAI Y-2 (trait anxiety) group 1 showed higher scores than corresponding group 3 only among males. Proportions of highest scores is higher among group 2 and 3.
The results showed a better emotional condition in CF transplant patients than controls. So, we observed that, despite weight of post transplant therapy, those patients perceive a good quality of life as possible consequence of a better lung function.
This preliminary study will be improving with data collection from all Italian CF Centres.

322 Prenatal diagnosis of cystic fibrosis: Parental opinion, clinical course in the first year of life and influence of having a sibling with the disease

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Objectives: Previous studies have shown the benefits of early diagnosis of CF regarding nutrition and clinical course. We aim to evaluate parental opinion concerning the importance of prenatal diagnosis (PND), and to assess clinical evolution of infants with PND in the first year of life, as well as the impact in bacterial isolates of having a sibling with CF.
Methods: Telephone survey of parents concerning the importance of PND. Retrospective analysis of patients with PND enrolled at the Specialized Center of CF (Lisbon) in the last 2 years regarding weight, bacterial isolates and complications in the first year of life.
Conclusion: Of the 4 patients with PND (3 girls), 2 were diagnosed due to hyperechogenic bowel and 2 had a sibling with CF. All parents decided to carry the pregnancy to term and all were full term births. On the survey, all parents considered PND and previous experience with CF to be useful in preparing for the newborn's condition, allowing for nutritional optimization and infection control practices. During the first year of life, 2 infants presented with complications (1 meconial ileus (MI); 1 rectal prolapse). At 12 months, all had weight above the 40th percentile (P), except for 1 (<P5), who was born with low birth weight and had MI. MSSA was isolated in all patients (1 with chronic colonization, as her brother); MRSA was isolated in 1 (as her sister); PA was isolated in 1 (only child). In conclusion, PND and previous experience with CF were considered beneficial by parents. Despite PND, clinical evolution was variable. Complications were independent from PND. Older siblings' bacterial pattern seems to constitute a risk factor for colonization.

323 Bringing bad news: The diagnosis of cystic fibrosis in childhood

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Background: The day parents are told the CF diagnosis is imprinted in their memory. The diagnosis changes their life radically, their hopes and dreams for the future are shattered and parents and families need to restructure their lives. It is important to understand how parents perceive and experience the CF diagnosis and investigate their needs.
Objectives: The aim is to evaluate parental experiences concerning the initial CF diagnosis, emotional reactions, information requirements and thoughts about caregivers' attitudes.
Methods: Parents of children with CF diagnosed during the past 5 years ($n = 35$) are interviewed using a semi-structured interview, including short questionnaires about emotions and feelings during the diagnostic stage and thoughts regarding the diagnosis and their future perspective.
Results: The initial diagnosis is generally given by a non-CF specialist (GP, pediatrician), followed by information from a CF specialist. Factors affecting the experience of the diagnosis are physicians' availability and attentiveness, their honesty and the comprehensiveness and pace of information. Shock, anger, stoic acceptance and denial are common first reactions. All parents prefer repeated information and value support of the multidisciplinary approach.
Conclusions: Parental experiences of the CF diagnosis are affected by many factors, e.g. the attitude of the physician, the content and timing of information and social support. Parents describe many different emotions during the diagnostic stage. The diagnosis is the starting point of a long-term relationship between patient, parents and CF team. 'Doing things well from the start' is an investment in the future.

324 First experiences with a patient education program for children with cystic fibrosis and their parents

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Objectives: Patient education is recognized as a necessary part of care for children with chronic diseases and their families. In contrast to other chronic diseases such as asthma, diabetes and atopic dermatitis, structured education programs for CF patients and their parents have not yet been developed and evaluated.
Methods: We report on a study conducted with the help of the German Ministry for Health in order to develop programs for children with rare diseases. Theoretical background and structure have been reported at the ECFC 2011. Now we are able to present the first results of qualitative focus group interviews after participation in the program. Quantitative evaluation was carried out with knowledge tests and questionnaires on satisfaction with the program and the results will be available within the next weeks.
Conclusion: Focus group interviews revealed a high emotional pressure in parents. They expressed the need for such an intervention early after diagnosis. The interdisciplinary structure of the program, as well as the group setting was highly appreciated. Main topics were hygiene problems and clinical manifestations of CF. The discussion on psychosocial topics was found to be helpful, especially reflecting the own well-being and to better use social resources was felt to be of great importance. The group composition in children and adolescents is difficult; it has to meet hygiene rules as well as coherent group constellations according to age and sex. The adolescents rated the program favourably. Particularly the diversified structure with short theoretical group sessions and much more active learning by doing sports was a positive experience.